



Consultation response

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Strengthening the NHS Constitution / Department of Health

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About Disability Rights UK

Disability Rights UK was formed through a merger of Disability Alliance, Radar and the National Centre for Independent Living on 1 January 2012. We aim to be the largest national pan-disability organisation led by disabled people. Our vision is of a society where everyone with lived experience of disability or health conditions can participate equally as full citizens.

Disability Rights UK's objectives are to:

- mobilise disabled people's leadership and control
- achieve independent living in practice
- break the link between disability and poverty
- put disability equality and human rights into practice across society.

Consultation response

Patient involvement

Q1. What are your views on the proposed changes to strengthen patient involvement in the NHS Constitution?

We welcome the proposed changes and the criteria on which they have been based (as published on page 8), but we do not believe that either criteria or resulting proposed changes go far enough. As a further criterion we would like to see 'patient and public voice & insight acting as key lever to system improvement'.

A further set of proposed changes would then include (but not be limited to):

- 'A right to full accessible and transparent information about factors that may affect the quality of NHS treatments and care such as payment systems set up for the NHS provider setting or the consultant, in particular: do certain payment systems, eg payment by results, incentivise the number of clinical procedures which may lead to harmful and/or unnecessary clinical procedures for the patient?
- A right to a second opinion in advance of decisions between treatment options
- A right to be supported in exercising choice, eg by a peer navigator
- A prospect for individual and collective choices to have a measurable impact on NHS services, commissioning and whole systems improvement

The greatest barriers to the proposed principles, pledges and rights coming true for patients and the public lie in the culture engrained in the NHS which is largely determined by the medical model. Day-in day-out patients experience a professional approach which upholds the clinician's opinion as the most legitimate signpost to drive action. Patients are seen as posing specific medical problems which can be isolated to be fixed rather than as assets and co-producers of a whole life pathway towards cure, recovery or improvement in quality of life and health outcomes.

Feedback

Q2. What do you think about our proposal to set out in the NHS Constitution the importance of patient and staff feedback towards improving NHS services?

We believe in extending (both real-time and more time-distant) feedback systems. However, without some of the above measures to recognise the substantial input from patients and the public, there will not be a sufficiently strong drive to act on

such feedback. While we consider the 'friends & family test' to be a valid item to measure service quality, we think there is a risk of losing this validity and patient engagement altogether if the test is applied without clear consequences, such as making payment systems dependent on achieving certain scores for example.

There is a wealth of feedback information that is relevant to specific clinical areas and also to people with long-term conditions more generally, and that relates to the choices people have taken when empowered to do so under personal health budgets. The insight expressed in these individual choices could directly inform innovation in the NHS – why do commissioners not systematically pick up the choices made under personal health budgets and incorporate them into the portfolio of services and support available to everyone?

Duty of Candour

Q3. Do you agree with, or have any concerns about, amending this pledge to make it more specific as suggested?

We support measures to achieve the proposed 'duty of candour' (to tell patients if something has gone wrong) through a contracted mechanism. However, disclosure of clinical treatments or procedures which have been harmful to the patient and/or unnecessary should not just be made to patients and relatives concerned. In addition to that and more than anything else, we need a far wider culture of clinicians admitting to such mistakes. There need to be serious efforts to establish a national record of treatment failures (and with information on local settlements) in order to foster learning for the future - including about how the role of patients as decision-makers themselves can be strengthened to prevent such failures.

We are awaiting the report of the Mid-Staffordshire Inquiry (announced for early February 2013) and hope to be able to relate to it with further comments and suggestions then.

Making every contact count

Q4. What are your views on including in the NHS Constitution a new responsibility for staff to make 'every contact count' with the aim of improving health and wellbeing of patients?

The individual clinical encounter is a core but by far no exclusive contributor to positive health outcomes and wellbeing. Yes, all opportunities should be taken "to talk to patients and carers about how to improve their health" but this should not be communicated as an attempt to hand over accountability so that patients become solely responsible for improving their health. To a great extent, (public) health is a

matter of improving social relations and reducing inequalities in income, housing and access to care and support for example. For clinicians there is a role to allow for and facilitate 'communicative space' which does not necessarily mean spending more time with a patient but rather shifting the focus on 'how' that time is spent.

Alongside any single clinical encounter the individual patient has a whole life to live which in all its domains determines their health and well-being. Individual and collective involvement has a direct impact on health outcomes. Advice and most importantly peer support (hearing from someone who has walked a similar path in the past) would empower the individual to contextualise a condition and make sense of it within their whole life domains. That is, the greater the extent to which someone is being involved in their care and support the greater will be their positive health outcomes. There are also multiple positive knock-on effects, including productivity gains. However, involvement, co-production, peer support and empowerment are not hardwired into the NHS Constitution to the extent we would have preferred to properly ensure 'The NHS belongs to all of us'.

Integrated care

Q5. Do the proposed changes to the NHS Constitution make it sufficiently clear to patients, their families and carers how the NHS supports them through care that is coordinated and tailored around their needs and preferences?

TripAdvisor-type quality ratings and access to care records as well as genuine opportunities to co-produce them, eg in mental health, are excellent levers to patient involvement as well as to integration: The individual will increasingly and most naturally own decisions affecting their health. At the same time these very same decisions taken by the individual will foster integration of services to fit around their needs, wishes and feelings.

But the system needs to adopt, too, in order to become more de-medicalised for example. Alternative payment systems (beyond Payment by Results) should be explored which link (clinician or hospital) pay to performance as measured not just by outputs but also by outcomes such as patient experience. Furthermore, integrated cross-sector pathways with bundled, proportionate tariffs should be developed and particular pathway stages (associated with specific outcomes) costed and allocated between a range of ('any qualified') providers – large and small. Individual and public involvement (as well as the commissioning decisions taken by personal health budget holders) could inform which types of support – including peer support – should be defined and integrated into those pathways.

We see great potential for a focus on common pathway points across specific conditions, eg on common experiences of barriers at diagnosis, early intervention, transition from social care to NHS Continuing Carer or back into employment,

acute care referral and discharge stages. This approach would yield valuable information on how services and support should be commissioned in a social rather than the current medical model dominated by a 'white coat syndrome'. We believe such community-driven and innovative partnership approaches to joint commissioning, (information) pathways, shared decision-making and integration should be featured and driven much more explicitly by the NHS Constitution.

Complaints

Q6. Do you think it is helpful for the NHS Constitution to set out these additional rights on making a complaint and seeking redress?

We agree that the NHS Constitution should outline more clearly the complaints process. See also above on question 3 ('Duty of Candour') our comment on preventing harmful and/or unnecessary procedures. Our main concern and interest is in giving the NHS Constitution greater traction.

Patient data

Q8. Do the proposed changes to the NHS Constitution make clear how the NHS will safeguard and use patient data?

Data are an important vehicle to join in and co-produce positive health outcomes – as we have elaborated on question five above in relation to quality ratings, access to care records and 'integration'. At the same time accessing and sharing patient data is also understandably a very sensitive area. We believe that consent should not be implied but explicit and actively obtained – wherever possible and including in unplanned care. Otherwise, the opportunity of expressed dissent needs to be highlighted. This is to respect the data protection principles but also to reinforce that patients need to be involved when their data are being shared – such data-sharing can also be a significant source of errors leading to harmful procedures.

We know that there are shortcomings in staff training on the Data Protection Act, and particular concerns are around bank staff who may not have access to secure in-house email accounts when being instructed to process personal data.

Staff rights, responsibilities and commitments

Q9. Do you agree with the proposed changes to the wording of the staff duties and the aims surrounding the rights and responsibilities of staff? What do you think about the changes

to make clear to staff around what they can expect from the NHS to ensure a positive working environment?

Q11. What are your views on the wording used to highlight the importance of ensuring that the tenets of dignity, respect and compassion are sufficiently represented in the NHS Constitution?

Strengthening the role (and satisfaction) of staff is intertwined with all other proposals made in the consultation text and with some of our own suggestions. We see huge potential of a more rewarding and effective workplace if the human non-medical dimension of care in the NHS is put on a par with medical tasks. NHS management should spread a far greater knowledge and understanding of the extent to which patient pathways, compliance and health outcomes are affected by allegedly *softer* factors such as dignity, respect and compassion.

Then staff would be able to meaningfully relate to an engagement framework in their Continuing Professional Development for example. We are concerned by a stereotypical call for more training, as frequently proposed especially for new NHS workers. Cultural change is not a question of training, values and competencies alone. As long as the NHS does not collect and spread evidence on the positive impact of patient voice & insight, peer support and non-medical responses, there will be no whole systems improvement. This needs to be reflected in new payment systems and cross-sector pathways as outlined above on question five on 'integration'.

Local authorities role

Q13. Do the proposed changes to the NHS Constitution make it clear what patients, staff and the public can expect from local authorities and that local authorities must take account of the Constitution in their decisions and actions?

We support the ambition to extend the remit of the NHS Constitution to local authorities in respect of their re-gained role in public health. We would add that social care also plays a public health role in its preventative effect on delaying NHS care. Furthermore, patient and public engagement need to be joined up with emerging structures such as local Healthwatch and Healthwatch England.

Raising awareness and embedding the Constitution

Q14. Have you seen further examples of good practice in raising awareness and embedding the NHS Constitution that should be taken into account in these plans?

Embedding the NHS Constitution must avoid tokenism, and this is best achieved by aiming for and demonstrating a tangible impact such as the national record on harmful and/or unnecessary procedures (referred to under question three) and by establishing and working with patient and public partnerships (eg building on local 'Centres for Independent Living').

Giving the Constitution greater traction

Q16. To help shape our future consultation, do you have views on how the NHS Constitution can be given greater traction to help people know what they should do when their expectations of the NHS are not met?

We would refer to our answer to question 11 and to our call for a 'feedback culture' in relation to a national record of harmful and/or unnecessary clinical procedures. Improvement must start immediately and not just 'after the event' of failure. A proactive approach would invest in building up patient resilience, social networks or family and friends support and patient confidence more generally.

In order to de-medicalise NHS workplaces and NHS culture, more fundamental whole systems improvement needs to be approached. Commissioning (including procurement and payment systems) is the key area which needs to better reflect the principles, rights and pledges enshrined in the NHS Constitution. Distinct agendas between a 'patient-centred' NHS that is 'clinician-led' need to be reconciled. We would also reiterate our point on integrated cross-sector pathways in response to question five which should be supported by clear and strong incentives for co-commissioning and sub-contracting to smaller providers (including local user-led organisations).

Finally, we would call for implementation case studies to demonstrate to both NHSCB and CCGs *how* the high level principles, rights and pledges in the NHS Constitution could be achieved meaningfully on the ground by way of co-production through patient and public partnerships (in line with the individual and collective involvement duties) – with numerous by-products on positive health outcomes and productivity gains. This should include insights and best practice on patient engagement channels, representation and influencing local decision-making as well as associated business cases for the NHSCB and CCGs.

We believe that, to this end, NHS services should generally be commissioned with three layers which should be independent of each other, that is one for core

provision (delivering the medical-technical care element), one for support (providing information and signposting including through peer navigators for example) and one for advocacy. It would be completely overwhelming for Healthwatch to be asked to act as the sole lever for community-based information, support and advocacy for patients and the wider public. A clear commitment to those three layers should be reflected in the NHS Constitution and in new innovative commissioning systems which we have outlined for social care in our programme on user-driven commissioning www.disabilityrightsuk.org/userdrivencommissioning.htm .

At the very least, the NHSCB and innovative CCGs should be appraised of the benefits of co-commissioning and sub-contracting to smaller community-driven agencies such as user-led organisations and the voluntary community sector at large.

Equalities

Q17. How can we ensure the NHS Constitution is accessible and useable to individuals of different backgrounds and to different sections of society?

Q18. Are there any ways in which the proposed changes set out in this consultation could have an adverse impact, directly or indirectly, on groups with protected characteristics? If so, how?

We believe that the proposals in the NHS Constitution and our own further suggestions help to reduce inequalities in access, experience and outcomes of NHS services – provided that measures are taken to incentivise the use of peer supporters/navigators acting as role models and early adopters of innovation in patient and public partnerships.